

Health Care at the Crossroads: *Development of a National Performance Measurement Data Strategy*



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Development of a National Performance Measurement Data Strategy

A background image showing three healthcare professionals in blue scrubs. A woman on the left is looking down at a laptop. A man in the center is looking at the laptop. A man on the right is looking at the laptop and holding a pen. They are all smiling and appear to be in a collaborative work environment.

Joint Commission Public Policy Initiative

This white paper emanates from The Joint Commission's Public Policy Initiative. Launched in 2001, this initiative seeks to address broad issues relating to the provision of safe, high-quality health care and, indeed, the health of the American people. These are issues that demand the attention and engagement of multiple publics if successful resolution is to be achieved.

For each of the identified public policy issues that it has addressed, The Joint Commission already has relevant state-of-the-art standards in place. However, simple application of these standards, and other one-dimensional efforts, will leave this country far short of its health care goals and objectives. Thus, this paper does not describe new Joint Commission requirements for health care organizations, nor even suggest that new requirements will be forthcoming in the future.

Rather, The Joint Commission has devised a public policy action plan that involves the gathering of information and multiple perspectives on the issue; formulation of comprehensive solutions; and assignment of accountabilities for these solutions. The execution of this plan includes the convening of roundtable discussions and national symposia, the issuance of this white paper, and active pursuit of the suggested recommendations.

This paper is a call to action for those who influence, develop or carry out policies that will lead the way to resolution of the issue. This is specifically in furtherance of The Joint Commission's stated mission to improve the safety and quality of health care provided to the public.

Preamble

Since the turn of the century, reliance on the use of performance measurement data has become a mainstay in the quality improvement programs of health care organizations across the country. More recently, increasing emphasis on the transparency of health care information, and the growing utility of performance data for all health care stakeholders have illuminated the significant issues that inhibit other important potential uses of performance measurement data, such as to support consumer decision-making and performance comparisons by policymakers and payers.

Most notably, insufficient attention has been paid to the data infrastructure that needs to be in place to support performance measurement activities. The framework for designing such a data infrastructure must address consumer expectations for data privacy, support a data highway that allows for data sharing and linkages, and operate under an agreed-upon set of rules and governance structure. These issues must be addressed expeditiously.

This report frames the fundamental issues and sets forth principles to guide the next steps in the development of a national performance measurement data system.

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Introduction

In today's health care environment, the meticulous collection and meaningful portrayal of relevant quality data and information are vital to health care organizations, practitioners, purchasers, oversight bodies, and the public. It is through such reliance on performance data that health care organizations and individual practitioners can determine priority areas for quality improvement, accrediting and regulatory bodies can evaluate performance, and purchasers and consumers can make informed health care judgments and decisions.

Increased recognition of the value of performance data has stimulated the development of major performance measurement initiatives and databases across stakeholder entities. Prominent among the measurement development initiatives are those of the American Medical Association (AMA)-convened Physician Consortium on Performance Improvement, the AQA,¹ the Centers for Medicare & Medicaid Services (CMS), the Hospital Quality Alliance (HQA), The Joint Commission and NCQA.² Several of these entities also maintain performance measure databases, as do a bevy of health plans, payers and professional disciplines.

Most performance measurement efforts tend to operate in isolation from one another to meet the specific needs of their sponsors. Frequently, data collection efforts are particular to specific care settings – such as hospitals or ambulatory care organi-

zations – or to particular payers, whether private or public. Data may also be collected as part of a clinical registry and specifically focus on one category of clinical services. Since data are collected and used in fragmented ways, they rarely provide a picture of the overall quality of performance for a specific clinician or organization, or how well patients fare, or the state of the public's health at-large. Further, the lack of data-sharing inhibits the ability to assess clinical episodes of care that are defined by the provision of services from multiple providers over time to treat a specific health condition.

The explosion of performance measurement efforts has increased system costs and the burden associated with data collection and reporting. It has also sometimes led to inconsistent portrayals of performance. Thus, the ability to share or merge data – especially standardized data – could lead to better use of system resources and mitigate the confusion that may result from contradictory assessments of performance.

For these reasons, a national strategy for the collection, aggregation, sharing and reporting of performance measurement data from across its sources is an urgent need. Indeed, the timely availability of credible, accurate and useful health care performance information is a fundamental public good.



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Introduction

In addition, harmonization of performance measurement efforts is important to achieving efficiencies in the measurement process and thus permitting more effective use of performance data. At the same time, the vagaries of illnesses, prevention and treatment options, settings of care, geography, insurance status, regulation, and professional preference make the development of a national performance measurement strategy that meets the needs of its many stakeholders highly complex. In addition, each database comes with its own data definitions, level of data quality, formats for storage and access, and policies that establish restrictions on its use.

There is also a clear and growing patient need for health care performance data that can be used in supporting decision-making, especially with the advent of consumer-directed health plans that are predicated on providing patients with more control over how their health care dollars are spent. The success of such plans depends upon the availability of credible, comprehensive data that are relevant to patient needs and can presumably drive market share. At the same time, concerns about protecting the privacy of personal health information in a digital age continue to be paramount. Recent high-profile incidents in which the security of patient-specific data was breached illustrate the vulnerabilities of large-scale electronic databases. These vulnerabilities must be addressed in order to engender patient trust in data sharing activities that are fundamental to accurate assessments of health care performance.

Among the basic components of a national performance measurement data strategy are a framework that establishes the rules that govern the national system, the expectations of users, and construction of a “data highway” that will allow data to flow to and from the national system. It logically follows that pursuit of a national performance measurement data strategy is necessarily a

collaborative endeavor – one which requires the active participation of all of its key stakeholders. For this reason, The Joint Commission convened an expert Roundtable comprising representatives of federal health care agencies, hospital and ambulatory care management, clinical practice, consumer advocacy organizations, public health, and health care payers and purchasers, as well as individuals with expertise in health care information technology and in performance measurement and reporting.

The Roundtable was charged to address the issues that underlie the development of a national performance measurement data strategy and to propose principles that should guide its development. Beyond the scope of the Roundtable was discussion of the specific measures that should be included in a national performance measurement strategy. Rather, the Roundtable focused on the overarching structure of such a national system. Among the specific issues addressed by the Roundtable were the users and uses of health care performance data; the evolution and adoption of electronic health records (EHRs) and their impact on data collection and reporting; potential constructs of a national performance data system; and ways in which to protect the privacy of patient information. This white paper represents the culmination of the Roundtable’s discussions.

A variety of issues constitute potential barriers to achievement of a national strategy. Chief among these are issues around patient confidentiality, data ownership and control, local versus national data uses, data stewardship, sources of data (e.g., claims versus clinical records), and the general lack of uniformity and standardization in performance measurement, particularly in ambulatory care settings. The following principles are offered to guide efforts aimed at resolving these issues and developing a national performance measurement data strategy.

Principles for the Development of a National Performance Measurement Data Strategy

A national performance measurement data system should:

A. Have the following qualities and characteristics:

- Be a credible source of high-quality, actionable, timely data.
- Embrace transparency and engender trust.
- Include a strategy for raising consumer awareness of the availability of publicly reported performance data and its benefits.
- Assure that the data and information provided are comprehensible to consumers at all literacy levels.
- Serve as a useful source for improving the quality and safety of care.
- Encourage the rapid adoption of information technology across all health care settings.
- Foster accountabilities among practitioners, provider organizations, payers, purchasers, patients, and communities for continuous improvement in performance.
- Be assured sustainable funding from public and private-sector sources.

B. Accommodate the following needs:

- Provide for performance measurement and data gathering at the patient, practitioner, provider organization, and population levels.
- Minimize the data collection burden at all levels of the system.
- Permit comparative data portrayals that are useful in supporting clinical decision-making, performance improvement, incentive payment programs, and consumer decision-making.
- Foster the utilization of performance measures – and particularly outcomes measures that are linked to evidence-based process measures – that address national quality goals and

high-impact, high-cost clinical conditions, including chronic diseases.

- Effectively protect patient privacy while also assuring broad access to meaningful and relevant performance data as a public good.
- Address information needs across the continuum of care so as to provide a longitudinal view of the quality and safety of patient care.
- Permit overviews of performance at the national level, as well as at regional and local levels.

C. Include the following design characteristics:

- Have an infrastructure that is based on common, interoperable information technology architecture.
- Utilize standardized, quality-controlled methods for gathering, validating, and aggregating performance data.
- Have as its locus an existing or new entity that provides effective stewardship for the system, and whose oversight actively involves public and private sector leaders.
- Permit the transmission of data from, and across, multiple databases.
- Provide for the establishment of consensus “rules of the road” respecting transparency and data access.
- Utilize an effective system for linking and matching patient records that protects patient privacy while also permitting expanded portrayals of practitioner and provider performance.
- Be in conformance with and support the data standards being developed through the National Health Information Network that will eventually permit the collection of performance measurement data as a byproduct of care delivery.

I. Create the Framework for a National Performance Measurement System

The Context

The environment in which health care is delivered today is fraught with tensions. While health care purchasers and payers are seeking ways in which to alleviate the burden of skyrocketing health care costs, health care professionals and the public are increasingly focused on preventable adverse events and missed opportunities to provide high quality care. The magnitude of these latter two problem areas were highlighted, respectively, in the Institute of Medicine (IOM) reports, *To Err Is Human* (1999) and *Crossing the Quality Chasm* (2001). As articulated in the second of these reports, reliance on performance data by providers of health care services – as well as patients – was envisioned by the IOM as an important way to improve quality and safety, while driving market share to high-performing providers. Among its rules for a transformed health system, the IOM called for patients to be in control of their care, and for there to be transparency of performance-related information – including information to help patients select health plans, clinicians and hospitals, and participate in shared decision-making.

In the intervening years, a flurry of activity has been directed toward improving health care quality

and patient safety. Out of this activity, certain conventions – such as “What gets measured, gets done” and “Focus on the system” – have become established. Growing numbers in health care have gradually moved away from the “name and blame game” in addressing preventable adverse events and have come, instead, to rely on data to guide evidence-based decision-making and improve the systems that support care delivery. While these latter efforts are promising, more has to be done to ensure the effective and ubiquitous use of performance measurement data across all health care delivery settings.

Increasing scrutiny of health care quality and patient safety, as well as concern over rising health care costs, have coalesced into a priority for greater transparency in health care delivery. Purchasers, payers, and patients – those who foot the bill – want to know the prices they are being asked to pay and the quality of care and outcomes they can expect from their investments. Consequently, significant efforts are underway to begin to measure the efficiency of care delivery as part of the larger quest for value-based purchasing of health care services.



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Actions recently taken at the federal level are fueling the drive for transparency of health-related information. In August 2006, a Presidential Executive Order was issued that requires federal agencies which administer or sponsor health programs to make information available to consumers respecting the quality and costs of services provided by doctors and hospitals. The Executive Order also requires these agencies and their contractors to promote the use of interoperable health care information technology products so that data can easily be shared. The Order further leverages federal agencies to offer health insurance programs that reward consumers who choose health care providers based on value and quality. Following on the Executive Order, the Centers for Medicare and Medicaid Services (CMS) has added certain cost and price information to its consumer Web site so that the public can access such information alongside data on hospital quality performance. In addition, the Department of Health and Human Services (DHHS) has been promoting the creation of value exchanges around the country that incorporate the Order's cornerstones of value-driven health care. These multi-stakeholder community organizations must also be committed to publicly reporting cost and consumer assessment of care data, as well as to fostering and rewarding improved provider and practitioner performance.

The importance of performance transparency is underscored by the existence of tiered health plans, in which beneficiaries incur lower out-of-pocket expenses for using "high-value" health care providers, as defined by the health plans, and by the introduction of Health Savings Accounts (HSAs), under which consumers pay for out-of-pocket expenses through tax-exempt savings accounts that are usually coupled with high-deductible insurance plans. HSA design anticipates

that consumers will spend their own money wisely and thus reduce overall health care spending. Such informed purchasing, though, must necessarily be based on the availability of comparative information on the costs and quality of care options. Without this, HSAs offer hollow promise.

For its part, the Centers for Medicare & Medicaid Services is leading an effort to align federal payment policy with the quality of care provided – a concept that has been widely adopted by private-sector payers as well. Health care organizations and physicians across the country are increasingly participating in a myriad of "pay-for-reporting" and "pay-for-performance" programs that entail collecting and reporting data on a variety of performance measures. CMS has strongly supported stepping up the performance measurement efforts of the HQA and AQA because their investment in arriving at new consensus measures is viewed as essential to meeting the Congressional pay-for-performance mandate and in assisting CMS in developing future payment policies. Similarly, CMS and other purchasers are investing in the development of measures of provider and practitioner efficiency, as well as funding efforts aimed at spurring the use of such measures.

In addition to its interest in "pay for performance," the Congress is focusing on performance measurement information in selected areas, such as a framework for publicly reporting health care-acquired infections. Many states already have mandatory adverse event and quality reporting programs that encompass a robust array of patient safety and health care quality measures.

Of note, there are already significant commercial insurer and purchaser plans to expand and consolidate performance measurement data. A prime example is Blue Health Intelligence (BHI), a comprehensive database of information under development by more than two dozen Blues plans in response to demands from consumers, employers and providers for “credible and actionable data to drive informed, evidence-based decision-making.”³ BHI seeks to become an unparalleled database in terms of its size and scope of information, as well as its commitment to the accuracy of its data.

While each of these efforts serves to meet specific interests, this piecemeal approach is falling short of meeting the needs of all of the various users of, and stakeholders in, performance data. Today’s performance measurement environment especially falls short of meeting the needs of health care consumers. Concern over the gap between the demand for performance measurement and reporting of the resultant data, and actual public access to useful performance information has led more recently to the publication of another IOM report, *Performance Measurement: Accelerating Improvement* (2006). This report, which highlights a set of foundational measures for quality improvement and calls for a coherent system of measurement and reporting, was the first in the Pathway series of reports that the IOM issued to address health insurance performance measurement programs, performance improvement programs, and payment strategies.⁴

Users and Uses

Users of performance measurement data have proliferated as the realization of the potential value of the information has grown. Today, data are used

by health care payers and purchasers in numerous local and regional pay-for-performance programs to determine performance and remuneration based upon compliance with preferred behaviors. Health care organizations and practitioners use data as a roadmap to guide improvements in health care quality and patient safety, and to fulfill their accountability obligations. Accrediting bodies, regulators, and certification boards rely on performance data in evaluating the organizations and individuals for whom they provide oversight. Public health officials examine performance data in the conduct of surveillance for disease outbreaks, as well as in population health management. And, to a lesser extent, consumers use data to guide choices of health plans, service providers, and individual clinicians.

Several initiatives aim to make performance transparent to patients. With a few clicks of a mouse, a patient living in Minnesota can learn which area medical practices are most effective in treating various health conditions – for example, diabetes, asthma, depression, high blood pressure – or proactively provide wellness services, such as pediatric check-ups or adult cancer screening. A parent can also find out which Minnesota practices most appropriately treat children’s colds and sore throats. Similarly, a patient living in Wisconsin can click through Web-based reports to learn how effectively area medical practices, health plans, and hospitals provide care for people with certain chronic illnesses or how well patients who have undergone specific surgeries, such as knee replacement or heart surgery, have done. Wisconsin patients can even learn how expeditiously appointments can be scheduled at area medical practices.

Minnesota Community Measurement and the Wisconsin Collaborative for Healthcare Quality – which are both alliances of various health care stakeholders – are participating in elaborate efforts to meet the health care information needs of their constituents. In so doing, they are bringing novel transparency to the delivery of health care that may ultimately serve to improve the quality of care in their communities.

For both of these initiatives, a major challenge has been the lack of engagement of consumers in accessing the available Web sites and using the data. A new grant program offered by the Robert Wood Johnson Foundation, called “Aligning Forces for Quality,” seeks to bring together health care providers, purchasers and consumers in 14 communities across the nation (including Minnesota and Wisconsin) to improve health care quality and decision-making for the chronically ill.⁵ The program focuses on driving progress in the ability of communities to improve quality, publicly report quality-related information, and engage consumers in their care and health care decision-making.

The limited use of performance information by consumers to-date appears to relate in part to a lack of awareness of its existence, as well as the limited availability of such data.⁶ In addition, consumers have received little guidance as to how to use this information.⁷ Further, consumers may view available data as not relevant to their specific interests, or simply may not be able to comprehend the existing data portrayals.⁸ Studies by Hibbard *et al* have shown that consumers have difficulty understanding technical indicators of quality, such as clinical performance measures, and the diffuse terminology used to report performance further compromises consumer understanding.⁹ This latter issue is a potentially significant barrier in a

society where nearly half of all adults have limited health literacy.¹⁰ Indeed, studies have found that information provided to consumers is not easily evaluable, and can lead consumers to make wrong choices.¹¹

With the advent of consumer-directed health plans, consumer-accessible performance reports will become increasingly important as consumers face more difficult health decisions. The American Association of Retired Persons has recommended that such information tools should require modest cognitive effort to use the information; help consumers understand the implications of their choices; and highlight the meaning of information that is important.¹²

Measure Standardization

Many of the measures that have proliferated to support various uses of performance information are typically “home-grown,” and are industry-segment and/or company specific. However, standardization of measure definitions and data collection processes is essential to the ability to produce comparable information, as well as to engender trust in the resultant information. By contrast, contradictory portrayals of similar performance breeds suspicion in data collection and aggregation efforts. At the very least, measurement and data reporting that are not done well can result in distorted perceptions of performance and also waste of precious resources. Importantly, the use of standardized performance measures and data collection processes can also serve to reduce the burgeoning “performance measurement burden” that exists today as a consequence of the accelerating demands for data by a variety of interested parties.

Standardization must specifically address the data elements that are collected for each measure. Failing this, measures that are similar but not the same, and whose results cannot be accurately compared, will continue to compromise performance measurement efforts and waste resources. In addition, best practices for data aggregation must be identified and applied consistently. Otherwise, existing and new databases may contain significant inherent inaccuracies that are invisible and therefore unknown to the users of the information. And while the reporting of performance data can and should vary based upon its uses and users, consensus and guidance on approaches to reporting can help to contribute to more effective use of such reports, especially among consumers.

Measure standardization falls under the auspices of the National Quality Forum (NQF), a private, not-for-profit membership organization created to assist with the development and implementation of a national strategy for health care quality measurement and reporting.¹³ The NQF relies on a formal consensus development process to review and endorse performance measures developed by various measure developers, and to set criteria to ensure that measures submitted to the NQF have the ability to support credible portrayals of quality-

related performance. Measure standardization also includes consensus-based protocols for collecting the data to reduce variation in results.

The work of the NQF provides a significant national service in standardizing measures and in ensuring that measures have been appropriately tested before they are actually used. Such reliance improves efficiency by reducing duplication, thereby lessening the data collection burden and effort associated with similar but slightly different performance measurement requirements. Ultimately, this standardization can also serve to ensure data quality and focus measurement activities on meeting national quality goals.

Unfortunately, numerous measurement activities around the country are still not engaged in the NQF process or any other comparable third-party validation process. Third-party validation is an integral element of trust in the value and quality of performance measures.



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Given the rise in chronic disease among the U.S. population, a national data strategy should especially encourage performance measurement and reporting focused on care for the chronically ill. The continuity and effectiveness of care for the chronically ill are of increasing concern to all health care stakeholders. However, the evaluation of such care is especially challenging because of the requisite need to aggregate data across multiple sites of care and across different payers.

Framing the Structure

Establishment of national quality metrics and a unified set of operating rules and standards for data collection and aggregation, as well as best practices and guidance for reporting and using both public and private-sector performance data, are requisite to the stewardship of a national performance data system.¹⁴ Establishing such a framework could facilitate the “interoperable” aggregation of measurement data and optimize its eventual use without limiting creative efforts to assess performance. Both the IOM, with its proposal for an independent National Quality Coordination Board (NQCB), and the AQA, with its proposal for a National Health Data Stewardship Entity, envision a combined public/private-sector model as the overarching structure for governing a national performance data system. The IOM report calls for a Board that would support the development of a national system for performance measurement and reporting. The AQA proposal addresses the same need but also emphasizes the importance of a uniform set of operating rules and standards for sharing and aggregating data.

These two approaches also differ with respect to the locus of the activity. The NQCB, as proposed, would be a federal entity with private-sector representation that reports to the HHS secretary, while the AQA stewardship entity would exist in the private sector and operate as a public/private-sector partnership modeled after the Financial Accounting Standards Board (FASB). Nevertheless, both proposals view public and private-sector collaboration as essential.

While the primary mission of a national health data stewardship entity would be to set uniform operating rules to support the collection and use of performance measurement data, it would also serve to foster future collaboration through the formulation of approaches that new participants would follow when designing their quality evaluation and data collection programs. The entity would also need to have strong working relationships with other key initiatives and organizations that have standard-setting roles in health care, including those relating to health information technology standards. Whatever model is chosen to provide direction and stewardship, the entity must be viewed as credible and trustworthy by all stakeholders. To that end, the AQA proposal establishes proposed precepts for the selection of a stewardship entity, and has since solicited comments on the potential critical roles of the entity through a Request for Information process.

Who Pays?

Any national standard-setting and governing entity will need to be sustainable to address the many complex challenges that are likely to confront the performance measurement data highway into the foreseeable future. Given the focus on a public/private-sector partnership, financing should logically come from both sectors. FASB, which is a 501(c)(3) not-for-profit organization, funds its activities through revenues gained from the sale of publications and the accounting support fees paid by issuers of securities.¹⁵ Similarly, a national performance measurement system held in the private sector could sustain its activities through the publication and sales of data standards, data validation activities and, perhaps, fees paid by users of the data. However, since there is no governing steward in existence today, it is not clear that a FASB model alone would provide sufficient basis for funding the comprehensive effort envisioned for such an entity. By contrast, the proposed Congressionally-appointed NQCB would receive funding directly from the Medicare Trust Fund. This is based on the thesis that a national performance data system devised to serve the public good merits at least some public financing. The issue remains as to what the cost of a stewardship entity would be and what level of public and private funding would be necessary to attain inclusiveness, effectiveness and sustainability.

National versus Local

Innovation in performance measurement and reporting is occurring in localities across the country. The Minnesota and Wisconsin initiatives are examples of such local innovation. These initiatives have been created and are evolving based upon the needs of their communities for specific health care information. A national data strategy should not stifle or supersede local efforts. Rather, it should support these efforts by serving as a national resource for standards to guide data collection, aggregation and reporting, and free local efforts from duplicating infrastructure work that has already been done. Importantly, a well-designed national strategy should also serve to ensure data quality by making available consensus standards for data auditing. Finally, a national strategy should include the capability to utilize data captured and aggregated at the local level to compare quality and cost information from state to state, track public health trends, and perform disease surveillance.



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II. Build a Data Highway to Support the Exchange of Health Information

Disparate Data

Current performance measurement activities directed to practitioners, hospitals and other health care organizations differ in their approach to data collection, including their approaches to data storage and retrieval. This presents challenges to data sharing and aggregation across sources of data. An effective performance measurement data infrastructure should be able to support these various types of efforts and allow for local control of data even when some or all of the information is shared for the public good.

For hospitals accredited by The Joint Commission, data for core performance measures are collected at the hospital through the hospital's participation in a third-party performance measurement system – a “data vendor” – that has been approved by The Joint Commission. These performance measurement systems are charged with ensuring the hospital's data quality and providing the infrastructure to support data collection and reporting to The Joint Commission. This approach could be described as creating new data – that is, the data did not exist until the core measures were applied, data was extracted from patient medical records, and the data were then reported to The Joint Commission and back to the hospital to support its own quality improvement activities.

The Joint Commission publicly reports performance data for accredited hospitals on its *Quality Check* Web site. Another hospital performance reporting activity is the HQA's *Hospital Compare* data reporting collaboration. *Hospital Compare* is a CMS-operated Web site that also publicly reports performance data – based mainly on the Joint Commission core measure set – from almost all U.S. hospitals. Today, more than 90 percent of the data on *Hospital Compare* are derived from the hospital data reported to The Joint Commission as part of its expectations of accredited hospitals.

By contrast, physician-level measurement activities planned by the AQA will be based on data derived from existing health insurance claims data. The AQA is currently piloting the reporting of physician-level performance data from a combination of public and private-payer data sources in six U.S. community reporting systems, including the Minnesota and Wisconsin data initiatives. It is important to be aware that the limitations of using claims data for performance measurement purposes, especially for evaluating the performance of individuals and small groups, are significant and need to be acknowledged in developing practitioner-level performance measures.

A separate infrastructure for physician-level performance reporting is through the CMS Physician Quality Reporting Initiative (PQRI). PQRI arose first out of an earlier CMS voluntary physician reporting effort that uses special codes in the claims payment system, and was later codified in the Tax Relief and Health Care Act (TRHCA) of 2006, which authorized CMS to establish a physician quality reporting system. The program is currently based on a foundation of 74 performance measures that include AQA measures. The application of these measures is expected to set the stage for future physician incentive payments.

There are also disease-specific data registries – such as that maintained by the Society for Thoracic Surgeons – that collect outcomes data respecting specific health care practices and procedures. The aforementioned Tax Relief and Health Care Act of 2006 specifically pointed to registries as an acceptable data source of performance information under the Medicare program's reporting efforts.

Performance measurement in physician practices can be especially challenging. In the U.S., the majority of patient visits occur in practices with four or fewer physicians.¹⁶ Small practices have fewer resources – such as information technology and personnel – to support performance measurement.¹⁷ Issues of patient sample size – a potential

problem for any physician practice – is magnified in small or solo practices.¹⁸ For these reasons, small physician offices have been excluded from many local quality measurement initiatives.¹⁹ Further, the heterogeneity of physician practices and specialties compounds the complexity of physician office-level performance measurement.²⁰

Other sources of physician and organization-level performance data – such as data derived from health information exchanges – are now beginning to emerge. Health information exchanges are generally designed to allow the electronic sharing of clinical information across disparate information systems.²¹ These health information exchanges most often serve a specific state or geographic area, and determine their own technical support and standards.²² The recent failure of the Santa Barbara County Care Data Exchange – an early, high-profile entry in the health information exchange arena – underscores the fundamental need that the information being exchanged and reported be of significant value to its users.²³ In the end, the Santa Barbara exchange data did not meet this user expectation.



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Health care entities such as nursing homes, home health agencies, managed care organizations, and end-stage renal disease facilities report performance data as a condition of their participation in the Medicare program. However, these data differ with respect to their origins and pathways of collection. For example, state survey agencies are involved in the collection of data for the nursing home Minimum Data Set (MDS) and, for home health agencies, the Outcomes and Assessment Information Set (OASIS) data. Regional renal networks help transmit quality-related data for dialysis facilities, while Health Plan Employer Data and Information Set (HEDIS) data comes through NCQA to CMS. Another stream of data will be created in 2008 when CMS will require eligible hospitals to publicly report H-CAPHS data. H-CAPHS is a standardized survey instrument and data collection methodology for measuring patient perspectives of their care. In the future, still another source of data may be created through the establishment of “patient safety organizations.” PSOs are defined and authorized in recent patient safety legislation that is currently awaiting implementing regulations through DHHS. The PSO legislation envisions a network of patient safety databases and the creation of a national repository of de-identified patient safety information drawn from the network of databases.

These disparate sources of potentially valuable health care information illustrate the need for a national system of performance data that relies on multiple data sources whose interoperability permits data exchange and aggregation when warranted. It also points to the need for consensus rules on data sharing, such as who may have

access to what data and under what circumstances. Another reality-based argument for a national system that draws upon multiple data sources is the importance of being able to track patient care longitudinally, as the patient traverses from one care setting to another. Such tracking often requires access to data sources in hospitals, practitioner offices, and home care agencies, among others.

The foregoing will, of course, be no easy feat. A new capability will be needed to “call up” and aggregate data from a large portfolio of data sources that encompass databases of varying size and scope, and reflect significantly different commitments to assuring data quality. Further, there is as yet no agreed upon taxonomy for many data elements, nor any defined interfaces to allow the aggregation and reconciliation of disparate data. In addition, the information technology necessary to capture data as a byproduct of care delivery -- and thereby alleviate the burden of retrospective data collection -- is not in widespread use, nor are there data standards to guide such data collection. Finally, there is no national patient identifier or established consensus for an alternative patient identification system that could allow a patient's care to be tracked longitudinally across the continuum of care while also satisfactorily addressing patient privacy concerns.

Information Technology

Information technology systems could alleviate much of the burden associated with data collection as long as the systems have been designed with the requisite functionality to support performance measurement activities. Specifically, electronic medical record systems need to be designed with the capacity to identify, aggregate, and transmit data elements that are integral to the performance measures being used both to provide efficiencies in data collection and to permit the creation of comprehensive performance profiles. Unfortunately, most current vendor-developed clinical information systems lack the ability to automate most performance data gathering efforts. Thus, this work largely remains a manual function performed by clinicians – typically registered nurses – who must page through multiple patient records to abstract needed data.

Another major obstacle to achieving automated data collection and reporting is the limited number of hospitals and physician offices that have implemented electronic health records (EHRs).²⁴ For hospitals, the substantial expense and lack of interoperability with other information systems are the most frequently cited obstacles to the widespread adoption of EHRs. For physician practices, the high costs, complexity of implementation and uncertain financial returns are the major factors that make such investments prohibitive.²⁵

To advance the adoption of electronic health records, DHHS created the American Health Information Community in 2005. This federal advisory committee includes representatives from both the private and public sectors and has been

charged to provide recommendations to DHHS on making health records digital and interoperable, as well as capable of protecting the privacy of patient information. Among the seven subsidiary workgroups now formed, the Quality Workgroup has been charged with determining and recommending how information technology can be used to automate performance measurement activities, including data collection, aggregation and reporting for current and future quality measures. This workgroup has initiated an effort with the National Quality Forum to identify standardized data elements that can be incorporated into the EHR as the foundation for beginning to automate a substantial portion of performance measurement activities.

Meanwhile, the Certification Commission for Healthcare Information Technology (CCHIT) has been established as a collaborative endeavor of the American Health Information Management Association, the Healthcare Information and Management Systems Society and The National Alliance for Health Information Technology to certify information technology products. DHHS awarded the CCHIT a three-year contract to develop certification criteria and an inspection process for ambulatory care and inpatient electronic health records, as well as for the “network components” through which EHRs can become interoperable and share information. The CCHIT has already begun to certify physician office-based EHRs, and is now addressing inpatient EHRs.²⁶ It describes its standards for interoperability as being at “an earlier stage of development” compared with its other standards development activities.²⁷

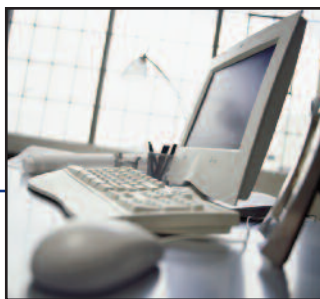
Personal Health Records

According to a recent survey conducted on behalf of the Markle Foundation, a majority of Americans would like electronic access to their personal health information because they believe such access will improve the quality of their care.²⁸ However, among those surveyed, there was strong concern about the privacy and security of their online personal health information.²⁹ Nevertheless, many saw important benefits that could be derived from the use of electronic personal health records (PHRs), such as reducing or eliminating costs by reducing the number of duplicative tests and procedures and their related costs, improving doctor-patient communications, and avoiding medical errors.³⁰

The cost and quality benefits that may be bestowed by personal health records have gained the attention and focused investment of a consortium of large employers, including Intel Corp., Wal-Mart Stores, BP America, Pitney-Bowes, Inc., and Applied Materials. The companies have joined together to provide PHRs for 2.5 million U.S.-based employees. The Web-enabled health records, which will be called “Dossia,” will be supported by a large data repository that will be able to link information on doctors, hospitals and pharmacies.³¹

The Dossia records will be private, secure and portable – whether the employee changes employers, doctors or health plans. Dossia records are being developed and administered by a third party to ensure that information contained in the Dossia record will only be available to the employee and those whom the employee grants permission. Dossia development is based on the Connecting for Health Common Framework, which provides a set of design and policy standards for the development and deployment of PHRs.

While PHRs support the patient’s access to and control of his or her information, data uploaded by the patient into the PHR may one day also become useful in supporting performance measurement activities. For example, blood glucose levels or blood pressure recordings measured at home could be used to measure the effectiveness of care processes and education provided to the patient.



Information technology systems could alleviate much of the burden associated with data collection as long as the systems have been designed with the requisite functionality to support performance measurement activities.

III. Engage Stakeholders and Engender Trust

Privacy Matters

To be successful, a national performance measurement data strategy must engender the trust of its stakeholders. The most apparent potential impediment to this trust is concern over the privacy of personal health information. Indeed, anxieties about protecting patient privacy remain an unresolved public policy issue.

Privacy concerns in the context of health care electronic databases are not without merit. Consider what happened to Thelma Arnold. For a brief period in the summer of 2006, AOL released on the Internet the search histories of approximately 650,000 of its customers. Despite the fact that AOL had replaced screen names with randomly assigned numbers, a researcher was able to quickly discern Ms. Arnold's identity and location. By cobbling together the topics that Ms. Arnold searched, much of Ms. Arnold's current life story was told -- from the mundane problems she grapples with to her more personal interests.

While Ms. Arnold's circumstances involved information held in the private sector, concerns over privacy are often magnified when governmental entities are the holders of large databases of personal health information. Witness the recent high profile instances where government-owned laptops containing sensitive information on large numbers of people were lost or stolen. The implications for identity theft and other potential misuses of the data were the subject of major news coverage and have significantly spurred public debate over whether new privacy laws are needed in an expanding digital age. Indeed, a recent survey conducted by the Markle Foundation found that eight in 10 Americans are very concerned about identity theft or fraud, as well as the potential for

their personal data to be used by marketers without their consent.³²

Privacy concerns can play out in the care encounter between patients and their physicians. Patients may be reluctant to reveal intimate information to their doctors for fear that once it has been entered into the medical record, it could be used as the basis for job or insurance discrimination, or that it will subject them to public stigma. In one study, more than half of respondents were very concerned about insurance claims information being used by employers to limit their job opportunities.³³ Approximately 15 percent of all patients engage in "privacy-protective behaviors" to keep their personal health information secret.³⁴ These patient behaviors include asking a physician to refrain from reporting certain health conditions or to report a false diagnosis; avoiding one's regular physician for certain health conditions; avoiding diagnostic tests; or paying out-of-pocket to avoid submission of a claim.³⁵

According to the Markle Foundation study, 75 percent of those surveyed said that the government has a role in establishing privacy protections for electronic health information.³⁶ To that end, consumer advocates are pushing for new legislation that will provide a more comprehensive set of protections than is afforded by the Health Insurance Portability and Accountability Act of 1996 (HIPAA) which focuses its governance of data on "covered entities." Many consumer groups believe that the HIPAA framework is severely lacking because of the substantial use of personally identifiable data outside of covered entities. They would prefer that privacy rules apply to a person's data wherever it may go or be used.

To assuage concerns over privacy, Connecting for Health has developed the following nine principles as part of its common framework for promoting private and secure health information exchange.³⁷

1. Openness and Transparency

There should be a general policy of openness about developments, practices, and policies with respect to personal data. Individuals should be able to know what information exists about them, the purpose of its use, who can access and use it, and where it resides.

2. Purpose Specification and Minimization

The purposes for which personal data are collected should be specified at the time of collection, and the subsequent use should be limited to those purposes or others that are specified on each occasion of change of purpose.

3. Collection Limitation

Personal health information should only be collected for specified purposes, should be obtained by lawful and fair means and, where possible, with the knowledge or consent of the data subject.

4. Use Limitation

Personal data should not be disclosed, made available, or otherwise used for purposes other than those specified.

5. Individual Participation and Control

Individuals should control access to their personal information:

- Individuals should be able to obtain from each entity that controls personal health data, information about whether or not the entity has data relating to them. Individuals should have the right to:

- Have personal data relating to them communicated within a reasonable time (at an affordable charge, if any), and in a form that is readily understandable;
- Be given reasons if a request (as described above) is denied, and to be able to challenge such denial; and
- Challenge data relating to them and have it rectified, completed, or amended.

6. Data Integrity and Quality

All personal data collected should be relevant to the purposes for which they are to be used and should be accurate, complete, and current.

7. Security Safeguards and Controls

Personal data should be protected by reasonable security safeguards against such risks as loss or unauthorized access, destruction, use, modification, or disclosure.

8. Accountability and Oversight

Entities in control of personal health data must be held accountable for implementing these information practices.

9. Remedies

Legal and financial remedies must exist to address any security breaches or privacy violations.

Patient Matching

For a national performance data system to be most valuable in transforming the quality of health care at the local level, it must be able to allow the assessment of performance across a single patient's continuum of care, including all of the providers of services involved in the patient's care, and bring the information together in a meaningful way. The aggregated results of such assessments – without patient identification -- could be shared nationally. The ability to match a single patient's record throughout the various linked databases that comprise the national data system would allow, for example, the assessment of the impacts of prevention, avoidance of duplicative services, the ability to link health outcomes to care delivery, and improvement of patient safety, e.g. through access to medication lists. Such a feature could also move the system capability beyond accountability into systemic improvement by, for example, permitting the longitudinal review of effectiveness and efficiency in relation to outcome measures. The NQF's Episode of Care Efficiency Work Group is working on a measurement framework that includes a vision of how efficiency can be measured by having information on patient care that spans the continuum of services.

However, these types of evaluations require the ability to identify relevant sources of patient data and then find within them the records that relate to the same person. This latter task is challenging because there is no uniform patient identifier used in the U.S. and it is not likely that there will be unless the significant existing concerns about privacy are addressed to the satisfaction of the public. Further, there is not yet a uniform set of conventions for recording and storing basic patient information respecting name, date of birth, address and other demographic information that may be used to match medical records. For example, Carlton Robert Jones may be listed as Carl Jones in one record, Carlton Jones in another, or C.R. Jones in a third database. Patients' street addresses and phone numbers change, and they are often not updated in records, especially at those sites of service that have infrequent contact with the patient. Unfortunately, many practitioners and providers are not attuned to the important nuances involved in recording and maintaining patient demographic information and the relevance of this effort to high priority professional and societal goals.



To be successful, a national performance measurement data strategy must engender the trust of its stakeholders.

To deal with the existing lack of uniformity in recording basic patient information, various methods and algorithms for linking records have been developed and are in use. These are usually based on probabilities of getting a true match, and none are perfect. A patient matching algorithm using preset criteria -- such as the patient's first name, last name, date of birth, zip code and gender -- are requisite to such a system. However, there is as yet no consensus across stakeholders as to what the patient matching criteria should be. A national performance measurement strategy will need to address best approaches that properly balance data access and patient confidentiality needs.

Since the patient's consent to be identified through matching across the system is imperative, it has been suggested that patients should be given the opportunity to opt into or out of such schemes.³⁸ For some patients, the fear of privacy transgressions may be outweighed by the benefit of having a complete medical history available to themselves and their caregivers across the care continuum. Significant attention must be paid to educating patients on the options and risks inherent in data sharing, and the value of performance measurement. To support this effort, development of "rules of the road" for an option-based national patient matching system should be a high near-term priority.

Interest and Trust

Indeed, patients need to understand the implications and benefits of a national performance measurement data strategy for their own care. The immediate fact is that the move to greater consumer accountability for health care decisions is already driving their greater reliance on data. And this move is creating greater alignment of goals amongst consumers, the provider community and health plans. Consumer advocacy groups need to engage early on in the development of the national performance data strategy to ensure that their constituents have access to the right information -- so that they will be able to know what they need to know in order to discern the cost, quality and value of health care services they wish or need to use.

Conversely, the risks of unreliable or invalid data or data portrayal must also be acknowledged. Bad data can misinform consumer decision-making and also place practitioner and provider reputations at risk. A national performance measurement system must be both well-designed and built upon a foundation of trust -- engendered through rules and principles that effectively address data use, integrity and reporting.

Conclusion

In the wake of the IOM's *Crossing the Quality Chasm* report, performance measurement has indeed blossomed, but the product to-date more resembles a hodge-podge of flowers and weeds than an orderly garden. The time has come to harness these efforts and energies and translate them into the powerful tools for decision-making and improvement that the IOM envisioned. The goal of the national performance measurement strategy described in this paper is just that. The challenges lie not only in constructing an effective operational system that serves the needs of all of its users, but also overcoming the significant barriers described earlier. These include burdensome data collection, lack of measure standardization, and patient privacy concerns, among others. Eventual success will require concerted and collaborative effort – guided by the principles set forth herein – by all of the parties at interest, as well as the investment of resources so often lacking in the past. In the end, doing all of this is simply a matter of will.

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Endnotes

- ¹ Formerly the Ambulatory Care Quality Alliance
- ² Formerly the National Committee for Quality Assurance
- ³ BlueCross BlueShield Association, www.bcbs.com/innovations/bhi
- ⁴ Institute of Medicine, *Performance Measurement: Accelerating Improvement*, National Academies Press, 2006
- ⁵ Robert Wood Johnson Foundation, Aligning Forces for Quality, www.forces4quality.org
- ⁶⁻⁸ RAND, “Consumer-Directed” Health Plans: Implications for Health Care Quality and Cost, prepared for the California HealthCare Foundation, June 2005, 24
- ⁹ Hibbard, Judith H., Slovic, Paul, Peters, Ellen, Finucane, Melissa L., “Strategies for reporting health plan information performance information to consumers: Evidence from controlled studies,” *HSR: Health Services Research*, 37:2, April 2002
- ¹⁰ 2006 National Assessment of Adult Literacy (NAAL), National Center for Education Statistics, U.S. Department of Education
- ¹¹ RAND
- ¹² Dubow, Joyce, *In Brief: Decision Making in Consumer-Directed Health Plans*, AARP Public Policy Institute Issue Paper, May 2003
- ¹³ National Quality Forum, www.qualityforum.org
- ¹⁴ AHIC Quality Work Group Vision Summary, January 31, 2007
- ¹⁵ Financial Accounting Standards Board, financial statements, 05 & 04, www.fasb.org
- ¹⁶⁻²⁰ Landon, Bruce E., Normand, Sharon-Lise T., “National Voluntary Consensus Standards for Ambulatory Care: Measurement Challenges in Small Group Settings,” June 2006, prepared for the National Quality Forum
- ²¹⁻²² eHealth Initiative
- ²³ Miller, Robert H., Miller, Bradley S., “The Santa Barbara County Care Exchange: What Happened?” *Health Affairs*, published online August 1, 2007.
- ²⁴ American Hospital Association, “Continued Progress Hospital Use of Information Technology,” survey, February 2007
- ²⁵ Hackbarth, Glenn, Milgate, Karen, “Using Quality Incentives to Drive Physician Adoption of Health Information Technology,” *Health Affairs*, 24, No. 5, 2005
- ²⁶⁻²⁷ Certification Commission for Health Information Technology, www.cchit.org
- ²⁸⁻³⁰ Connecting for Health, Markle Foundation, National Survey on Electronic Personal Health Records, November 2006
- ³¹ McWilliams, Gary, “Big employers plan electronic health records,” *Wall Street Journal*, November 29, 2006
- ³² Markle Foundation, December 2006
- ³³⁻³⁶ California HealthCare Foundation, National Consumer Health Privacy Survey, 2005
- ³⁷ Connecting for Health Common Framework, April 2006, www.connectingforhealth.org
- ³⁸ Safran, C., Bloomrosen, M., Hammond W.E., *Toward A National Framework for Secondary Use of Health Data*, published by the American Medical Informatics Association, September 2006

